

MA Expert Panel on End of Life Care

Meeting #2
DRAFT MINUTES

June 8, 2009, 5:30-8 pm MA Department of Public Health

DEVAL L. PATRICK Governor

TIMOTHY P. MURRAY Lieutenant Governor

Participants: Lachlan Forrow, James Conway, Dominique Kim, Alice Bonner, Andy Epstein, Artemis March, Susan Dale Block, MD, Robert C. Buxbaum, MD, Charlotte Yeh, MD, Christine McCluskey, Craig Schneider, Georgia Maheras, Muriel R Gillick, MD, Jack Evjy MD, Marilyn Kramer, Marita Prater, Mary Ellen Foti, MD, Mary Valliere, MD, Pat Noga; Patricia Jehlan; Peg Metzger; Rigney Cunningham; Robert Schreiber, MD; Ruth Palombo; Stancel M. Riley, Jr., MD; Stan Eichner, JD, Diane Stringer, Jack Evjy, MD, Pat Noga, Paul Spooner, Joanne Wolfe, Maria Regan, John Auerbach, Tracy Gay, Nancy Ridley

Unable to attend: Alice Wolf, Marylou Buyse, MD, Sharon Gale, Thomas P. Sellers, John Chai, Andrew J. Billings, Arlene Lowney, MD, Marilyn Travinski, Diane Bergeron, Julie Rosen, Chuck Koplik

Observers: Sandra Korman, Anita Phipps, Candace Savage, Iyan Romm

Topic	Discussion	Action Items
Welcome/ Introductions	 Lachlan welcomed group. Brief update was given on the Expert Panel web-site, a link from the "End of Life and Chronic Disease Committee" website will take you to: http://www.mass.gov/?pageID=hqccterminal&L=4&L0=Home&L1=The+Council&L2=About+t he+Council&L3=Meeting+Schedule+and+Materials&sid=Ihqcc&b=terminalcontent&f=expert_panel_on_end_of_life_care&csid=Ihqcc A shorter site name will be sent the panel soon. 	Core Planning Group to finalize expert panel member list based on input from group today and before Meeting #2 on June 29.

Data Presentations	Presentation #1: "Respectful End of Life Care Takes the Limelight	Core planning group
	in Massachusetts", James Conway.	to send answers to
	Full presentation on QCC Expert Panel website:	questions per
	http://www.mass.gov/lhqcc/docs/expert_panel/2009_06_08_Respectful_Home%20Care.ppt	
	http://www.mass.gov/lhqcc/docs/expert panel/2009 06 08 Respectful Home%20Care.ppt Concluding slide: Solutions emerging and await Expert Panel's Findings Declare the current state unacceptable Declare our commitment to work together Education of staff and patients, families, consumers Design a system to support palliative and EOL care Palliative programs in all hospitals, LTC, home, office Durable orders move with patient across the system Keep patients out of hospitals, ICUs, SNFs Transparency of key measures Reduce variation in resource use at the last 6 months Align Incentives, including payment Assure there is a workforce	presentation to Panel, as part of supportive info recommendations.
	minutes or shortly thereafter.	
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Data Presentations	Multiple comments/questions from one panelist:
(CONT)	1. Need to build this prototype presentation – how do we get this message out to AAA network,
	organized medicine (Mass. Medical Society), AHA?
	2. How do we get Dartmouth Atlas information out?
	3. How do we manage message of need for change?
	4. Should we be transparent with these results in MA?
	5. Need to get work on MOLST out to MA citizens?
	6. Do we need to have public comment on MOLST form?
	7. Can we get this form out to MMS?
	8. How does Hospice of North Shore/other hospices on North Shore drive hospice referrals to % it does?
	9. Does Hospice of North Shore success have to do with palliative care provided in acute hospitals & having Kaplan Family Hospice?
	10. Does palliative care service access decrease ICU use and increase referrals to palliative care/hospice?
	Presentation #2: "Progress on MOLST Demonstration Project in MA", Peg Metzger, MA MOLST Project Consultant Full presentation on QCC Expert Panel website: (COMING)
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	Panel members submit questions, to be reviewed, answered, and sent back to the panel with the minutes or shortly thereafter.
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Data Presentations (CONT)	 Not bundling can result in inappropriate orders – i.e. CPR but no intubation. (JW) Can physicians honor orders written by NP's? Lawyers? Patients themselves? The MOLST recognizes that it is reasonable to request intubation but not CPR. Will the Comfort Care form be modified to allow this as well? 	Lachlan to contact Joan Teno about MA/MN comparison data.
	Presentation #3: Hospice of the North Shore, Diane Stringer Full presentation on QCC Expert Panel website: (COMING)	
	 Dr. Susan Block: From perspective of teaching hospitals we need hospices. They are often the best places for discharge, best for pts, best for families, a zillion reasons. I think that availability and visibility of palliative care in hospitals makes hospice more visible, including hospice beds at MGHWe do 20 different teaching sessions/year about hospice for our residents. We provide training for people that go on to work as medical directors of hospices. Aim is for it to be seamless. Rigney Cunningham: Care is not always seamlessmaybe at MGH it facilitatesin some places it doesn't. Dr. Block suggested talking with Joan Teno who could analyze her database to look at MA v. MN – there 100k people in her database. [Lachlan will contact Joan.] Dr. Charlotte Yeh: Liked the idea; The more we can be in synch nationally the more likely we can be effective. Fabulous job getting us organized. One thing not explicitly stated – all of this work is really centered around the patient and family's personal preferences – this has got to be the public message, that this is really about meeting your preferences. 	
	Panel members submit questions, to be reviewed, answered, and sent back to the panel with the minutes or shortly thereafter.	

Workgroup Framework (based on 2008 NPP priority for palliative care)

Dominique presented the Core Group's proposed framework for workgroup structure and process to reach recommendations by Oct. 31, 2009.

(Full presentation on QCC Expert Panel website. (COMING SOON)

Comments from Panel including suggested edits to the visual framework:

- Multicultural issues: Several panel members expressed concerned that the "multicultural/racial disparities" may not be integrated into the other 4 or be measured; Suggestion to make that an overarching theme in the "umbrella".
 - One member noted that the Panel itself does not represent a diverse population. Core group responded that several multicultural members were included in the initial panel invitation but could not partake. Core group to try to add more representation; Suggestions from Panel welcome.
- ✓ Regulatory authority: It would be good to know what <u>authority</u> exists in regulations, legislation, etc. – if DPH has authority we take one tack; if DPH doesn't maybe we need to <u>give</u> the authority.
 - ➢ Jim's response: we need to be both sensitive to the regulatory environment but not be encumbered by it. Need to understand current legal/regulatory environment...if we are looking at transformational change we can't be doing a bunch of little things
- ✓ Patient-centeredness: Dr. Robert Buxbaum: if you are going to talk about an "expert panel" I don't think that there are any better experts than people who have been through the experience. Could change #3 to Pt/Family communication w. physicians. That seems to be the model for the Obama administration approach to health care reform.
 - ➤ Jim Conway: Schwartz Center, Health Care for All, others have helped us in that. You cannot have a workgroup w/o consumer/patient engagement
 - ➤ Lachlan Forrow: Every graphic and document we produce/vet through this panel needs to be centered in patient values and preferences. All agreed and this will be emphasized in the revised visual (the workgroup on patient<-> provider communication).
- ✓ Continuum of care: Ruth Palombo: implicit but not explicit that we want to look at all of this work across the lifespan; it should be explicit in there, that it is across all populations and age ranges.

Workgroup	✓ Research/Evaluation/Evidence:
Framework CONT.	Tom McLaughlin: As an evaluation researcher, the graphic reminded him of systems of care for children and other well-intentioned initiatives to improve
	humane dimensions of carewould "never get anywhere at NIH". How
	can/should we approach evaluation and how we sell that, especially to
	insurers? Best thing we could do for children was come up with medical
	accountability model – things like social support are extremely difficult
	constructs to measure. "I would like to go to xxx and say "we should be
	reimbursing for this, and I need to have a cogent argument for saying this is worthwhile"
	Dr. Jack Evjy: You can measure the state of a pt; the degree to which you are
	affecting structural changes, functional changes, degree of distress, etcone can begin to bring measurable parameters.
	 Jim Conway: There are lots of areas we don't need evidence forthere's a lot of
	research out thereas part of the work groupone of the things that we've said
	is the status of the evidencedoes X look like a good thing to do but we need
	more evidenceCarolyn Clancy is very involved w. NPPher work is going to
	see funding growSenator Kerry's office already in touch w. Secy Bigbyif as
	part of the workgroup we could figure that out there could be opportunities to get
	those questions answered. We also met w. MAHP (Marylou Buyse) – couldn't
	get all the payers to agree to do something together because that would be
	collusion, but all said they looked forward to working w. us once we have
	recommendations.
	✓ Affordability: Muriel Gillick: Appreciates that from practical/policy perspective we need
	to consider whether things are affordable, but some things have no cost or would pay for
	themselves – how would we know that something is affordable, or from whose
	perspective does it need to be affordable.
	o Dr. Charlotte Yeh: Met w. CMO of Aetna who's excited about compassionate
	care model for AetnaThere's no specific time limit for hospiceThey are
	working on a business model. (Lonnie Reisman is CMO but different a MD runs
	the compassionate care program for them.)
	 We're talking about a huge reallocation of \$\$ from inpatient services to
	ambulatory/other settings – a huge dislocationwhere are we going to get all
	the people to start doing things and stop doing othersprisons are net importers
	of \$\$ for a lot of communities in rural areas. In Mass. the support of this system
	constructs the bricks and mortar that we see around town. Without the business
	model this will continue to be the right thing to do.
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Workgroup Framework CONT.	 ✓ Equitable care: Paul Spooner- Another concern is lack of benefits for Medicaid recipients. "It's great that Aetna is thinking about a more appropriate form of coverage and carethe communities I see are stuck with the bottom of the barrel of care/receiving gov't benefits and a lot are ending up in the hospitals and nursing homes. That's where their end of life care occursthey are getting a second class level of end of life care." We need to take into consideration equitable level of care, in addition to affordable. ✓ Dominique Kim/core group will add "equitable" to the criteria on the visual framework (alongside achievable affordable, actionable, and cost/financing) ✓ Jim Conway: We'll need to discuss with Secretaries Sibelius & Bigby special allocations from Medicare/Medicaid and some experimentationWhat are the key components relating to Medicare/Medicaidit's great to talk about commercial players, but if we want to move the state we need to talk about commercial players, but if we want to move the state we need to talk about both. ✓ Dominique Kim: A portion of Rockefeller bill addresses reimbursement for palliative care (consults) among CMS patients. ✓ Role of Expert Panel past Oct. 31, 2009: Chris McCluskey asked what would happen to the Expert Panel after recs are submit. ➢ Lachlan: will not exist. The Expert Panel's recommendations will need to include some about what entities (in a form follows function way) will be necessary and most effective in achieving the goals we identify as important. ➢ Dominique: At a recent Schwartz Center event on compassionate care Dominique has sent the Expert Panel membership list to the community providers and groups present that night. Broader, before and after Oct. 31, ongoing communication between panel members and collaborators in their state-wide communities is essential, to support and drive the upcoming recommendations. (Susan Block spoke at this event and here	Dominique/core group to amend visual framework to include edits, e.g. adding "special populations" and "evidence" as overarching themes and "equitable" as a criteria for recs; Also highlighting patient- centeredness as a core tenet.
Wrap-up/Next Steps	 Meeting #3:June 29 Meeting #4: Sep. 9 Final meeting being scheduled for early to mid October, to present a final draft of recommendations for final edits. June 4 are: June 8, June 29, and Sep. 9. 	